Enhancing Care Coordination Through Patient & Family Engagement

LESSONS FROM OPENNOTES AND INFOSAGE

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Medical College of Wisconsin

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Disclosures

- I serve on the Advisory Board of QUR Health

- Full Information about disclosures available at http://scholar.harvard.edu/crotty/
Clinical Informatics
What was old is new again

**BUSINESS PRACTICE**

The following material is based on a public relations manual issued by the Public Relations Department of the American Medical Association.—Ed.

**USE OF THE TELEPHONE**

Like an extra arm to the physician is that wonderful but pesky invention—the telephone. It is an instrument, however, that requires special handling. During the doctor’s office hours the telephone should never be left unattended. If there is only one
“The patient is the least utilized resource in health care”
“Flipping Healthcare”

ESSAY

Flipping healthcare: an essay by Maureen Bisognano and Dan Schummers

Maureen Bisognano and Dan Schummers argue that to meet today’s healthcare challenges, we need to flip our thinking to develop innovative models of care that can improve health, improve care delivery, and lower costs.

Maureen Bisognano president and CEO, Dan Schummers chief of staff

4 hours  8,756 hours
Welcome, Frog F Kermit.

Schedule

Manage Appointments

OpenNotes

We are pleased to announce that in 2013, many Beth Israel Deaconess patients on PatientSite will be invited to read the health care notes their doctors, nurses and other clinicians write after an appointment or discussion.

We call this OpenNotes. To learn more about OpenNotes, click here.

Education

MedlinePlus

Trusted Health Information for You
'Nothing About Me Without Me'
OpenNotes Invites Patients To Read Chart

- 84% of BIDMC patients opened at least one of their notes
- 82% GHS patients opened at least one note
- 47% of HMC patients opened at least one note
- 20-42% of patients reported sharing notes with others
OpenNotes


P.114 Primary Care Doctors and Their 20,000 Patients

I. Patient Direct Access To Notes Through Web Portal

C. No Access To Notes

O. Survey Measures

84% reported better understanding of their health and medical conditions

73% felt better prepared for visits

84% reported remembering the plan for their care better

84% felt more in control of their care

70% reported taking better care of themselves (incl. med adherence)
What is the reason for today’s visit? [Text]

Who is your primary care doctor? Dr. Bradley Croft

Doctor’s address: B1 14LA

Who referred you to us? Dr. Bradley Croft

Where should we send copies of your office notes? Patient Site

Is today the result of a work injury? [Yes/No]

Was it an auto accident? [Yes/No]

Date: [__/__/__]

Name: [__]
## PCPs’ Main Concerns

### Survey Results About Impact on Workflow

<table>
<thead>
<tr>
<th>Concern</th>
<th>Pre-intervention (%)</th>
<th>Post-intervention (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>More time addressing patient questions outside of visits</td>
<td>42</td>
<td>3</td>
</tr>
<tr>
<td>More time writing/editing notes</td>
<td>39</td>
<td>11</td>
</tr>
</tbody>
</table>

*Email message volume did not change*

The Bottom Line For PCPs

- After a year, PCPs were asked:

  *Taking all considerations into account, I would like my patients to continue to be able to see my visit notes online.*

- At least 3 out of 4 said YES, and even though some said NO, at the end of the trial, not one doctor asked to turn it off for their patients.

More than 4.8 million patients have easy access to their clinician's notes thanks to OpenNotes
Questions about Open Notes Remain

• Will patients continue to read notes?
• Can open notes improve patient safety?
• How should we teach open notes, and incorporate sharing of notes into residency programs?
• How can we best support caregivers?
Unadjusted Note Viewing Over Two Years at Both Sites

Notes viewed within 30 days of availability (%)

Time

Notifications to view notes stop at GHS and continue at BIDMC

Courtesy John Mafi MD
Patient Safety

• Conceptually, patients reading notes may enhance patient safety:
  ◦ Reflection and follow-through
  ◦ Detection of errors / stop chart propagation
  ◦ Information transmission to caregivers

BIDMC Process For Patient Feedback

Patient reads note and is invited to give feedback in the reporting tool at the end of the note.

Patient Relations reviews all responses.

Safety Concern? yes 22%

Patient Relations reaches out to patient and/or clinician to discuss concern and then closes the loop with patient.

Aggregate data on survey feedback is captured in database for study.

Sales

- Medications: 30%
- Missing Element: 22%
- Symptoms: 17%
- PMHx: 13%
- FamHx: 10%
- Exam: 9%

Courtesy of Sigall Bell MD
Expanding To Residency Clinics

• Identify resident/fellow and preceptor attitudes about sharing notes with patients
• Assess specific educational needs, programmatic policy recommendations, and approaches
Results of Mixed Methods Study

- 4 Main Themes
  - Transparency of Information
  - Ideology of a Note
  - Trust Issues
  - Time Pressures
“I kind of think of it like bedside rounding, when we round at the patient's bedside rather than spending 30 seconds in that room and spending an hour outside of their room.... I like the idea - I think it would improve on my relationship with my patients for them to know that I spent this time on their note.”
“I don't think they should be made available. I think resident notes are a tool for education.”
“...you will be more concerned about writing the note in a way that the patient is going to understand rather than focusing on what you are doing...”
“You could get some aggregate data on how your patients actually feel about how you are [doing]... I've never actually seen any of that stuff coming back to me.”
“When I have talked with my colleagues and peers about it, a lot of the anxiety stems from just that we don't want - we are afraid that something, that this is going to trigger some catastrophic level of worry in our patients that is just going to be another fire that we have put out.”
“You are given a 10 minute window of time in which to see this patient, discuss this patient, and direct the resident, fellow, as to what the plan of action needs to be; then together go into the room and talk to the patient. And now you want to be able to sit and scrutinize every word written in a note. That doesn’t fit the template. That’s a huge problem.”
In his notes, the doctor called me "mildly obese." This prompted immediate enrollment in Weight Watchers and daily exercise. I didn't think I had gained that much weight. I'm determined to reverse that comment by my next check-up.

Crotty: Unpublished Data
Caregiving and Portals

- 65 million in US estimated to be “informal” caregivers
- Transparency to improve quality
- Family help in self-management and medical decision-making
- Caregiver - Clinician partnership
It really is much easier to show my family who are also my caregivers the information in the notes than to try and explain myself. I find the notes more accurate than my recollections, and they allow my family to understand what is actually going on with my health, not just what my memory decides to store.
The Problem

- Aging creates healthcare decision-making, information management, and communication challenges, for elders and their families
- Care coordination is exceptionally challenging
- Respecting the elder’s preferences and priorities is often lost in translation
Care of Frail Elders

- Poor Communication, Coordination, and Collaboration with care system
- Community resources fragmented
- Burden on children can become part-time job
- Cognitive and physical function wax and wane
- Demographics create a world-wide imperative!
Goals of InfoSAGE

- Identify the information needs of elders (75+) and those helping to care for them
- Create a “living laboratory”
- Longitudinally study elder and family collaborative interactions
- Evaluate effects on Communication, Coordination, and Collaboration
- Be useful to families!

InfoSAGE
Information Sharing Across Generations
Goals of InfoSAGE

- Identify the information needs of seniors and caregivers
- Create a “living laboratory”- InfoSAGE, a family-centered information management and collaborative environment for seniors and families.
- Longitudinally study elder and family collaborative interactions and information management behaviors in the context of real healthcare decision-making and care transitions.
- Evaluate the extent to which InfoSAGE improves Communication, Coordination, and Collaboration for elders and their family.
- **Be useful to families**
Messing Among 75+ Users

- Medication Mgmt: 30%
- Results Mgmt: 24%
- Coordination: 20%
- Clinical Concern: 20%
- Clinical Update: 15%
- General Health Ques.: 8%
- Visit Follow-Up: 3%
- Mental Health Concern: 2%

Content analysis, n=99 messages

Patient | Supporter
---|---
Medication Mgmt | 30% | 0%
Results Mgmt | 24% | 6%
Coordination | 20% | 3%
Clinical Concern | 20% | 0%
Clinical Update | 15% | 0%
General Health Ques. | 8% | 0%
Visit Follow-Up | 3% | 0%
Mental Health Concern | 2% | 0%

Crotty et al. Presented at AMIA Symposium 2014
5 Key Insights From Focus Groups

- Must be assertive and/or present to find information.
- Many seniors and families use their (offline) social networks and word-of-mouth first, Internet second.
- Participants want an elder’s medical records accessible to all providers involved in the elder’s care.
- Seniors desired information to help the “middle of the night problem,” and families needed crisis communication support.
- Too much confidentiality.
Information Sharing Preferences

It’s Complicated!

- Elders & children have different perspectives
- No one size fits all
- Useful to have entire picture
- Unanticipated problems with sharing
- Don’t spy on me
- It’s all about control
Some families are very much in control of everything. I have a daughter who can run the world, she thinks she can. When my husband would ask her sometime to help with something, he's always sorry he asked her because she then takes over.
Program Features

• Communicate updates about health, wellness, events with your network of friends and family.
• Keep your medication list up to date, and share it among different caregivers and family members.
• Keep a “To Do” list that facilitates family and friends to help out as needed.
• Search for health information from trusted websites.
• Record your personal history and share pictures with your family.
Synthroid 100 mg (1 mg)
Lasix (Furosemide) 20 mg
Citalopram HBR Celexa 40 mg
Protonix Pantaprazole 40 mg (20x)
Os-Cal Calcium + D3 500 mg
Probiotic Phillips or Florastor (250 2x a day)
Activia
Multi Vitamin Centrum Silver
Senokot every day or as needed
Miralax Powder in water as needed
Colace (CVS Stool Softener) as needed
Depuvite Preserve Vision
 Bayer Aspirin 81 mg
Cyter (or Claritin) as needed
Prilosec 0.25 mg as needed
NIHSeniorHealth: Hip Replacement - Who Needs a Hip Replacement?

nihseniorhealth.gov
The most common reason for hip replacement is osteoarthritis. Osteoarthritis occurs when the cartilage covering the ends of the bones where they meet to form...

Hip Replacement: MedlinePlus

www.nlm.nih.gov
Hip replacement is surgery for people with severe hip damage. The most common cause of damage is osteoarthritis. Osteoarthritis causes pain, swelling, and...

Hip joint replacement: MedlinePlus Medical Encyclopedia

www.nlm.nih.gov
Most of the time, hip joint replacement is done in people age 60 and older, but many people who have this surgery are younger. Younger people who have a hip...

Hip joint replacement - series: MedlinePlus Medical Encyclopedia

www.nlm.nih.gov
Updated by C. Benjamin Ma, MD, Assistant Professor, Chief, Sports Medicine
Privacy
Evaluation

Research Schedule

Index Elder
Family Member

Family Member
Family Member

Family Members may be invited to join the network, either by the index elder or Family Member A.

General usage data are collected among participants not under informed consent to detail the size of the index elder’s network and determine how all members contribute to care coordination.

- Under Informed Consent
- InfoSAGE Platform Utilization Data
  - Study Team Contact / Survey
  - Study Team Contact / Brief Update
- Calendar
- Microblog
- Search
- Resource Guide
Lessons I’ve Learned

• It’s not about the technology, but technology implemented correctly can help scale benefits.
• Patients, and their family and friends, are the least utilized resources in healthcare.
• Clinicians are concerned about new communication channels, though often fear outsizes realized “burden.”
• We need process and technology improvements so that helping is not equated with burden, both for families and clinicians
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